

SEVEN TIPS

for dealing with a rare disease

Finding a way to constructively deal with a chronic disease is usually a major obstacle for those affected. This is especially true in the case of rare diseases where uncertainty is high and there are few people affected.

This checklist is designed to serve as a guide when taking the first steps. The aim is to support those affected in gaining greater control over their new situation and in this way becoming a manager of their own disease. The checklist was created in collaboration with the Global MPN Scientific Foundation and professor Haifa Kathrin Al-Ali, Internist at the University Hospital Halle (Saale) and Director of the Krukenberg Cancer Center Halle.



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serve as a guide.*

1.

Inform yourself – but properly!

It's well known that knowledge empowers people. So it's important to be well informed of the various aspects of one's own disease. When gathering information, however, pay attention to the source. Only reliable information helps to properly manage the disease and avoid uncertainties. The internet in particular is a frequent source of misinformation and we're often confronted with superficial knowledge in other situations that can be detrimental to the progression of the disease or quality of life. In Facebook groups especially, it has been shown that it is not uncommon for false knowledge to be spread. So make sure you scrutinize where the information is coming from or verify it in a conversation with your physician.

You'll find reliable information:

- By talking to specialized health staff (general and specialist physicians, nursing staff, study nurses etc.)
- As part of the continued education offers for the public at universities
- At information centers of patient organizations
- At public health facilities

... I have read
this on the
internet ...

Oh ... please
be careful!



Who has not experienced this? Sometimes it's hard to ask for help.



2.

Ask your physician

Prepare yourself well for the conversation with your physician. Write down your questions and take this list with you. Otherwise, you may forget crucial points in the heat of the moment. Consider taking someone along to accompany you during the conversation. This person can support you in emotional situations and potentially also jot down parts of the conversation. In addition to your questions, it's also advisable to take along your medical history and findings. Feel free to speak openly – all of your questions are important! No question is too “stupid”. Attached you'll find an extra checklist for the conversation with your physician.

3.

Get in contact with others affected

It's not just comforting to see that you're not alone in this unfamiliar situation, which is usually perceived as threatening. In many cases, it's helpful to have an example of how you can overcome challenges to find a suitable solution for yourself.

When people with similar needs come together, it strengthens them in many ways: Alongside exchanging experiences or passing on tips and tricks, those affected also achieve greater visibility and are able to lend greater weight to their needs and demands.



A checklist can be helpful when talking to a physician.

For more information, please refer to the “Checklist for the conversation with your physician”.

4.

Find some support

Everyone is able to better find their way out of a crisis when they have the right support to fall back on. Usually, it's a combination of measures and coping strategies that help those affected to face the disease head-on – or perhaps even to accept it as a friend. After all, it may potentially accompany you throughout your lifetime. So don't hesitate to look for suitable offers or take advantage of them.

Examples:

- Patient organizations
- Partners, family and friends
- Governmental bodies that offer funding, psychological or socio-legal advice
- Psychological support

A wide range of offers is available from the government. Patient organizations usually have a good overview here, and will be able to provide you with customized advice and help you navigate the jungle of offers.



Have the courage to reach out to others who are affected, for support and exchange.

5.

Pay attention to your body

In a crisis situation in particular, it's important to take good care of yourself and keep your body in shape as best you can. Speak to your physician about how you can best care for your body and stay fit. Find out, for example, what type of movement is advisable, what applications are sensible and beneficial and what diet is most suitable in your individual case. But also listen to your body if you feel unwell. If this feeling persists for longer, contact your attending physician.

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What can I do for myself and my body?

Setting yourself realistic goals can be motivating!



6.

Make use of psychological services

Psychological services can be very helpful for anyone affected. A psychological discussion can be a safe haven where one is free to express one's worries and doubts. What's more, psychological experts are trained to find ways out of crisis situations together with their clients and support them in rediscovering their inner sources of power.

Psychological support is offered by the following, among others:

- Hospital psychologists
- Established psychologists and specialized psychotherapists
- Some patient organizations
- Governmental bodies or community facilities

For more information, get in touch with your physician or pharmacist.

7.

Name your personal goals

Anyone who wants to overcome a distance needs a goal they can aim towards. This applies to real journeys, but can also be translated to psychological processes. So take some time to think about how you would like to shape your life despite your disease and what small and large milestones you would like to achieve. It's not easy to juggle all your needs at once. Start by setting yourself small goals and expand them as you go. Experiencing success can be incredibly inspiring.

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